

Turkmenistan

Situation analysis of the boys and girls with disabilities

«Is there a child who does not dream of being counted and having her or his gifts and talents recognized? No. All children have hopes and dreams – including children with disabilities. And all children deserve a fair chance to make their dreams real.»

*Anthony Lake,
UNICEF Executive Director, SOWC 2013*



THE SURVEY ON THE SITUATION OF CHILDREN WITH DISABILITIES WAS COMMISSIONED BY UNICEF TURKMENISTAN IN 2014 WITHIN THE FRAMEWORK OF THE ONGOING COOPERATION WITH THE GOVERNMENT OF TURKMENISTAN.

The purpose of the survey has been to better understand who are the children with disabilities and their well-being, including those in institutions, as well as gain better insights into the accessibility and availability of social services for children with disabilities.

This study presents the findings and conclusions based on the situation for boys and girls with disabilities in three regions of Turkmenistan. As a result of these findings, a draft action plan and vision for children with disabilities which have been developed in consultation with key stakeholders and decision-makers.

Methodology

The survey was based on interviews with the parents or main caregivers of 150 children with disabilities living in families and 151 children with disabilities in residential institutions. Directors of 10 specialised residential institutions and 1 specialised day school were also interviewed and over 30 parents of children with disabilities as well as of typically developing children were consulted in focus group discussions.

An extensive desk review also informed the methodology for the survey and the findings including international good practice, national legislation, policy and institutional arrangements for children with disabilities in Turkmenistan, and relevant studies and research reports from Turkmenistan. Importantly, the methodology was informed by the model of disability described in the WHO International Classification of Functioning – Children and Youth (ICF-CY), as shown in Figure 1.

Definition

There is no agreed international definition of disability nor a standard to measure it. Definitions of disability in different surveys and within the same country are non-comparable.

Purely medical definitions used in the past are giving way to definitions that incorporate continuous measures of the activities that people can undertake, the extent of participation in society and social and civic life, as well as the role of adaptive technologies (Filmer 2005). Efforts to

develop measures of disability have accordingly focused on measures that capture activity limitations and participation restrictions (Mont 2007, Mitra et. al. 2011).

Most use the International Classification of Functioning, Disability and Health (ICF) definition of disability, developed by the WHO in 2001. There are three disability measures from ICF:

- Impairment: presence of impairment intrinsic to the individual.
- Functional: limitations experienced with particular bodily functions such as seeing, walking etc, irrespective of whether the individual has an impairment or not.
- Activity: limitations in activities of daily living such as bathing or dressing.

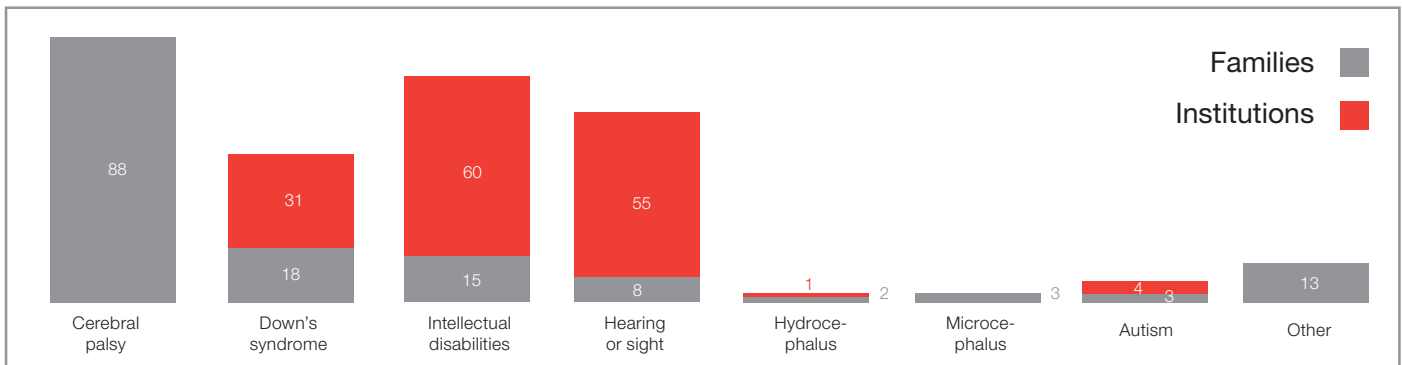
Code of Turkmenistan “On Social Benefits” of 17th March 2007 (with amendments and completions introduced by the Laws of Turkmenistan: No 234-III of 23.10.2008 and No. 23-IV of 06.03.2009) provides a definition of the notion of “person with disability”, that is, a person with limited vital activity resulting of physical or mental impairment. Limited vital activity of a person is manifested in full or partial loss of the person’s capacity or possibility to perform work activity, self-service, independent movement, orientation, communication, control of own behaviour (Art. 81). Besides, the Code identifies categories of persons with disabilities, including children with disabilities under 16 (Art. 82).

The disability category is determined by the Medico-Social expert commission (MSEC), depending on the level of citizens’ vital activity limitation, caused by physical or mental impairment. There are three categories of disability, according to Art. 84. The Code provides a system of actions aimed to ensure social support to citizens in case of disability.

Main findings

The number of children with disabilities in Turkmenistan is likely to be much higher than those who are officially recorded as receiving the child disability allowance, which was the only official statistical data provided to the survey. It is likely that there are more than 14,445 boys and girls with disabilities in Turkmenistan and that, in keeping with international prevalence levels, the number of children with moderate to severe disabilities is likely to be at least from 1%-4% of the child population aged 0-17 years.

Figure 2 Medical diagnosis and care setting N=301 children,
Source: diagnoses reported by survey respondents, authors' calculations



Disaggregated inter-sectoral data is not readily available which could help to establish more exactly the rate of child disability prevalence in Turkmenistan.

A medical model of disability dominates public and private discourse about disability in Turkmenistan with the child's condition being seen mainly as an illness that needs treatment. Parents report mixed experiences of health services, but the only assistive devices or equipment readily available are orthopaedic shoes.

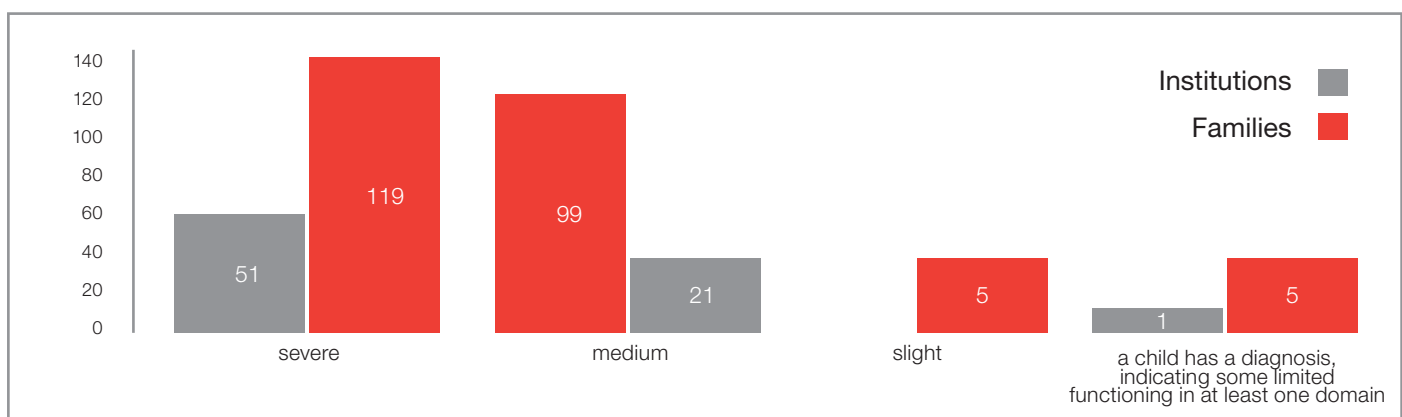
An extensive network of both residential and non-residential special education schools and preschools form a largely segregated education system for children with disabilities. Many children, especially children with motor disabilities, are not in any form of education. Many children in families who are in education are being educated through home-based teaching.

Most extra-curricular activities for children with disabilities are based in segregated residential schools and are not readily accessible to children with disabilities living in families.

Disability allowances and extended family support and care form the two main pillars of the system of social support for children with disabilities and their families. While in most cases extended family members help to provide care for children with disabilities, in 12-20% of cases this type of help may not be available and children are more likely to be placed into residential forms of care as a result. Around 30% of primary caregivers for children in families say they need help with learning to communicate well with their child.

Most families receive disability allowances, but around 15% of the children in families who took part in the survey do not receive any state social assistance in this way.

Figure 3 Level of functioning and care setting N=301 children
Source: P4EC CEE/CIS Consultancy group/ OPM based on levels of functioning reported by survey respondents, authors' calculations



Disability diagnosis happens late for some children, or not at all for children with some types of disorders including Down’s syndrome and autism spectrum disorders. Parents report mixed experiences of the process of disability certification.

Children with more severe levels of disability and functional disorders are more likely to be living in families than in institutions, especially children with motor disabilities. Many children in institutions have regular daily or weekly contact with their families. High levels of interaction with siblings are recorded for most children in families and many in institutions. Around 40-50% of children with disabilities in both families and institutions have friends.

Around one third of children in families are accessing some types of additional social services in their communities, mainly from the Khyakimlik, NGOs and public organizations. Most parents and institution staff do not know about any social services or support.

Staff in the health and education systems in some cases stigmatise children with disabilities and this behavior reflects widely societal attitudes. Some children with disabilities are at risk of being isolated both within their families and excluded from social interaction as a

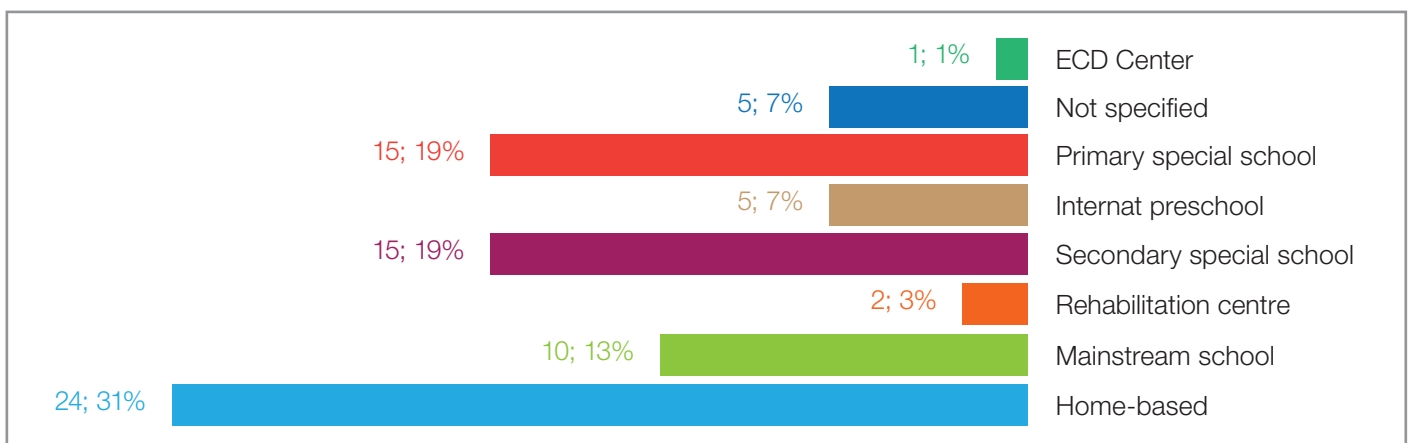
whole. Attention to preparation for independent living and employment for young people with disabilities are not being sufficiently addressed on the whole either by parents or residential schools, especially for children with more severe disabilities.

The main needs for support identified by parents of children in families and carers of children in institutions are:

- Support with providing day to day care in the home for some children
- Day care and respite care for some children and families
- Improved and strengthened parenting and care skills including: alternative communication where needed, lifting and carrying, child development
- More information about play, leisure and after school activities; health, education, community services; social services
- Assistive technology and devices
- Appropriate diagnostics and medical treatments
- Inclusive community and education services, play and leisure
- Preparing for independent living

Figure 4 Education settings of 77 children in families who are in education

Source: survey respondents and authors’ calculations



Conclusions

The system of extended family care combined with disability allowances seems to ensure that many children with disabilities are receiving adequate care in their families. If they live in special boarding schools, they seem to be maintaining regular and frequent contact with their families in many cases. It is clear, however, that some families need extra support from outside the extended family as there may not be extended family members available or willing to provide needed support.

Detailed assessments are needed to establish the level of need for additional services at the level of Etraps

and Velayats, but it seems possible that many of the existing residential residential schools and preschools could be transformed to provide mainly day school education services with resources being diverted into improved school transport provision.

There is a need to modernise understanding and knowledge of disability among health and education system specialists and to ensure that assistive devices and new technology become available to children who need them, especially children with cerebral palsy. Health services are of mixed quality and there is an urgent need to update knowledge of disability among medical personnel.

Parents of children with disabilities on what they want from education:

“The child studies at home. But we have a problem now – a residential school has opened, but they say we shouldn’t go to the boarding school. I don’t know (whether to transfer). Some people say that the residential school is good, and others say it’s better to study at home. At school they ask them to wear diapers, but he tells us when he wants to the toilet, I don’t want diapers... I wanted to take the child to school on the 1st of September, bought a shirt for him, but the teacher said I shouldn’t”.

“It’s every parent’s dream for their child to go to school”.

“The education has to correspond to his level of intellectual development since his intellect is intact, but a regular school wouldn’t take him” (survey respondent, about a child in residential special school)”.

“She attends residential school No. X. I would like her to go to a mainstream school. But they wouldn’t take her - they say there is a special school for such children. She just has one sick leg – a club-foot. She is a twin. One goes to school, and the other doesn’t. She has such sad eyes, she tells me: “Mom, let’s go with her”.

Source: focus group participants unless otherwise indicated

Information about disability generally and specifically about a model of disability based on the UNPD and the ICF needs to be widely disseminated in order to challenge stigmatisation of children with disabilities among the public and in the health, education and social assistance systems.

Draft Vision and Action Plan for Children with Disabilities in Turkmenistan

The development of policies and programmes for children with disabilities and their families should

build on the existing strengths of the current situation – strong extended family support for most children and families, free of charge health services, extensive provision of specialised education services, disability allowances being received by most families – in order to work towards a more equitable and inclusive society where children with disabilities are able to fully realise their rights.

Priorities going forward based on the survey findings are identified as:

1. Creation of social services that can support families to provide adequate care of their children with disabili-

ities. Activities and actions include detailed needs assessments to establish the type and scale of services needed; training of social workers and other specialists; piloting of new services such as day care, respite care, home care, individual assistants and supported independent living for young people; monitoring, evaluation and national roll-out of effective services.

2. Strengthen access to modern assistive devices and technology. Activities and actions include assessing the need for each type of device giving priority to children's mobility devices such as wheelchairs; train staff and establish new specialists in the latest assistive technologies; modernise existing manufacturing; define policy on the provision of assistive devices.

3. Training and education of staff – modernisation of existing curricula and introduction of new specialisms in the higher and secondary education system including: ergotherapy and physiotherapy specialisms; child neurology and psychiatry; audiology, ophthalmology, pediatrics, neurology and orthopedics; social pedagogues, special teachers, psychologists, speech therapists.

4. Communication campaign to address prejudice and stigma and promote inclusion – advertising clips on television; information events in schools and kindergartens; encourage and facilitate communication and interaction between children with disabilities and those without disabilities; information events for parents at schools and kindergartens

5. Ensure statistics and relevant data are available and can be used in planning, implementing and monitoring. Actions include: create an inter-ministerial data protocol for gathering relevant administrative data from the Ministry of Health and Medical Industry, Ministry of Education and Ministry of Labour and Social Protection

6. Improve options for accessible transport

7. Introduce employment and careers advice programmes for young people with disabilities

The full survey report is available at UNICEF Turkmenistan Country Office

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